

111TH CONGRESS  
1ST SESSION

# S. 981

To support research and public awareness activities with respect to  
inflammatory bowel disease, and for other purposes.

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IN THE SENATE OF THE UNITED STATES

MAY 5, 2009

Mr. REID introduced the following bill; which was read twice and referred to  
the Committee on Health, Education, Labor, and Pensions

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## A BILL

To support research and public awareness activities with  
respect to inflammatory bowel disease, and for other  
purposes.

1       *Be it enacted by the Senate and House of Representa-*  
2       *tives of the United States of America in Congress assembled,*

3       **SECTION 1. SHORT TITLE.**

4       This Act may be cited as the “Inflammatory Bowel  
5       Disease Research and Awareness Act”.

6       **SEC. 2. FINDINGS.**

7       Congress finds the following:

8               (1) Crohn’s disease and ulcerative colitis are se-  
9       rious inflammatory diseases of the gastrointestinal  
10       tract.

1           (2) Crohn's disease may occur in any section of  
2           the gastrointestinal tract but is predominately found  
3           in the lower part of the small intestine and the large  
4           intestine. Ulcerative colitis is characterized by in-  
5           flammation and ulceration of the innermost lining of  
6           the colon. Complete removal of the colon in patients  
7           with ulcerative colitis can potentially alleviate and  
8           cure symptoms.

9           (3) Because Crohn's disease and ulcerative coli-  
10          tis behave similarly, they are collectively known as  
11          inflammatory bowel disease. Both diseases present a  
12          variety of symptoms, including severe diarrhea, ab-  
13          dominal pain with cramps, fever, arthritic joint pain,  
14          inflammation of the eye, and rectal bleeding. There  
15          is no known cause of inflammatory bowel disease, or  
16          medical cure.

17          (4) It is estimated that up to 1,400,000 people  
18          in the United States suffer from inflammatory bowel  
19          disease, 30 percent of whom are diagnosed during  
20          their childhood years.

21          (5) Children with inflammatory bowel disease  
22          miss school activities because of bloody diarrhea and  
23          abdominal pain, and many adults who had onset of  
24          inflammatory bowel disease as children had delayed

1       puberty and impaired growth and have never  
2       reached their full genetic growth potential.

3           (6) Inflammatory bowel disease patients are at  
4       high risk for developing colorectal cancer.

5           (7) The total annual medical costs for inflam-  
6       matory bowel disease patients are estimated at more  
7       than \$2,000,000,000.

8           (8) The average time from presentation of  
9       symptoms to diagnosis in children is 3 years.

10          (9) Delayed diagnosis of inflammatory bowel  
11       disease frequently results in more-active disease as-  
12       sociated with increased morbidity and complications.

13          (10) Congress has appropriated \$3,480,000  
14       from fiscal year 2005 to fiscal year 2009 for epide-  
15       miology research on inflammatory bowel disease  
16       through the Centers for Disease Control and Preven-  
17       tion.

18          (11) The National Institutes of Health National  
19       Commission on Digestive Diseases issued com-  
20       prehensive research goals related to inflammatory  
21       bowel disease in its April 2009 report to Congress  
22       and the American public entitled; “Opportunities  
23       and Challenges in Digestive Diseases Research: Rec-  
24       ommendations of the National Commission on Di-  
25       gestive Diseases”.

1 **SEC. 3. ENHANCING PUBLIC HEALTH ACTIVITIES ON IN-**  
 2 **FLAMMATORY BOWEL DISEASE AT THE CEN-**  
 3 **TERS FOR DISEASE CONTROL AND PREVEN-**  
 4 **TION.**

5 Part B of title III of the Public Health Service Act  
 6 (42 U.S.C. 243 et seq.) is amended by inserting after sec-  
 7 tion 320A the following:

8 **“SEC. 320B. INFLAMMATORY BOWEL DISEASE EPIDEMI-**  
 9 **LOGY PROGRAM.**

10 “(a) IN GENERAL.—The Secretary, acting through  
 11 the Director of the Centers for Disease Control and Pre-  
 12 vention, shall conduct, support and expand existing epide-  
 13 miology research on inflammatory bowel disease in both  
 14 pediatric and adult populations.

15 “(b) GRANTS.—The Secretary, acting through the  
 16 Director of the Centers for Disease Control and Preven-  
 17 tion, may award grants to, and enter into contracts and  
 18 cooperative agreements with, a patient or medical organi-  
 19 zation with expertise in conducting inflammatory bowel  
 20 disease research to develop and administer the epidemi-  
 21 ology program.

22 “(c) RULE OF CONSTRUCTION.—Nothing in this sec-  
 23 tion shall be construed to limit the authority of the Cen-  
 24 ters for Disease Control and Prevention to support a pedi-  
 25 atric inflammatory bowel disease patient registry.

1 “(d) AUTHORIZATION OF APPROPRIATIONS.—There  
2 are authorized to be appropriated to carry out this section,  
3 \$1,500,000 for each of the fiscal years 2010 through  
4 2014.

5 **“SEC. 320C. INCREASING PUBLIC AWARENESS OF INFLAM-**  
6 **MATORY BOWEL DISEASE AND IMPROVING**  
7 **HEALTH PROFESSIONAL EDUCATION.**

8 “(a) IN GENERAL.—The Secretary, acting through  
9 the Director of the Centers for Disease Control and Pre-  
10 vention, shall award grants to eligible entities for the pur-  
11 pose of increasing awareness of inflammatory bowel dis-  
12 ease among the general public and health care providers.

13 “(b) USE OF FUNDS.—An eligible entity shall use  
14 grant funds under this section to develop educational ma-  
15 terials and conduct awareness programs focused on the  
16 following subjects:

17 “(1) Crohn’s disease and ulcerative colitis, and  
18 their symptoms.

19 “(2) Testing required for appropriate diagnosis,  
20 and the importance of accurate and early diagnosis.

21 “(3) Key differences between pediatric and  
22 adult disease.

23 “(4) Specific physical and psychosocial issues  
24 impacting pediatric patients, including stunted

1 growth, malnutrition, delayed puberty, and depres-  
2 sion.

3 “(5) Treatment options for both adult and pedi-  
4 atric patients.

5 “(6) The importance of identifying aggressive  
6 disease in children at an early stage in order to im-  
7 plement the most effective treatment protocol.

8 “(7) Complications of inflammatory bowel dis-  
9 ease and related secondary conditions, including  
10 colorectal cancer.

11 “(8) Federal and private information resources  
12 for patients and physicians.

13 “(9) Incidence and prevalence data on pediatric  
14 and adult inflammatory bowel disease.

15 “(c) ELIGIBLE ENTITY.—For purposes of this sec-  
16 tion, the term ‘eligible entity’ means a patient or medical  
17 organization with experience in serving adults and chil-  
18 dren with inflammatory bowel disease.

19 “(d) REPORT TO CONGRESS.—Not later than Sep-  
20 tember 30, 2010, the Secretary shall submit to the Com-  
21 mittee on Energy and Commerce of the House of Rep-  
22 resentatives, the Committee on Health, Education, Labor,  
23 and Pensions of the Senate, and the Committee on Appro-  
24 priations of the House of Representatives and the Senate,

1 a report regarding the status of activities carried out  
2 under this section.

3 “(e) AUTHORIZATION OF APPROPRIATIONS.—For the  
4 purpose of carrying out this section, there is authorized  
5 to be appropriated such sums as may be necessary for  
6 each of fiscal years 2010 through 2014.”.

7 **SEC. 4. EXPANSION OF BIOMEDICAL RESEARCH ON IN-**  
8 **FLAMMATORY BOWEL DISEASE.**

9 (a) SENSE OF CONGRESS.—It is the sense of Con-  
10 gress that—

11 (1) the Secretary of Health and Human Serv-  
12 ices, acting through the Director of the National In-  
13 stitutes of Health and the Director of the National  
14 Institute of Diabetes and Digestive and Kidney Dis-  
15 eases (in this section referred to as the Institute),  
16 should aggressively support basic, translational, and  
17 clinical research designed to meet the research goals  
18 for inflammatory bowel disease included in the Na-  
19 tional Institutes of Health National Commission on  
20 Digestive Diseases report entitled “Opportunities  
21 and Challenges in Digestive Diseases Research: Rec-  
22 ommendations of the National Commission on Di-  
23 gestive Diseases”, which shall include—

24 (A) establishing an objective basis for de-  
25 termining clinical diagnosis, detailed phenotype,

1 and disease activity in inflammatory bowel dis-  
 2 ease;

3 (B) developing an individualized approach  
 4 to inflammatory bowel disease risk evaluation  
 5 and management based on genetic suscepti-  
 6 bility;

7 (C) modulating the intestinal microflora to  
 8 prevent or control inflammatory bowel disease;

9 (D) effectively modulating the mucosal im-  
 10 mune system to prevent or ameliorate inflam-  
 11 matory bowel disease;

12 (E) sustaining the health of the mucosal  
 13 surface;

14 (F) promoting regeneration and repair of  
 15 injury in inflammatory bowel disease;

16 (G) providing effective tools for clinical  
 17 evaluation and intervention in inflammatory  
 18 bowel disease; and

19 (H) ameliorating or preventing adverse ef-  
 20 fects of inflammatory bowel disease on growth  
 21 and development in children and adolescents;

22 (2) the Institute should support the training of  
 23 qualified health professionals in biomedical research  
 24 focused on inflammatory bowel disease, including pe-  
 25 diatric investigators; and



1           (3) the Institute should continue its strong col-  
2           laboration with medical and patient organizations  
3           concerned with inflammatory bowel disease and seek  
4           opportunities to promote research identified in the  
5           scientific agendas “Challenges in Inflammatory  
6           Bowel Disease Research” (Crohn’s and Colitis Foun-  
7           dation of America) and “Chronic Inflammatory  
8           Bowel Disease” (North American Society for Pedi-  
9           atric Gastroenterology, Hepatology and Nutrition).

10          (b) BIENNIAL REPORTS.—As part of the biennial re-  
11       port submitted under section 403 of the Public Health  
12       Service Act (42 U.S.C. 283), the Secretary of Health and  
13       Human Services shall include information on the status  
14       of inflammatory bowel disease research at the National In-  
15       stitutes of Health.

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